Sedgwick County, Kansas IDD-MH Service System Evaluation

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Executive Summary

This evaluation was conducted by members of the UNH Institute on Disability National Center for START Services ® (NCSS) and funded by the Sedgwick County Developmental Disability Organization (SCDDO) as part of their ongoing effort to improve services for individuals with intellectual/developmental disabilities (IDD) and mental health (MH) service needs (IDD-MH). It was conducted with input from citizen volunteers with the active support of SCDDO. The evaluation process highlights the self-reported experiences of service users, families, and providers regarding the effectiveness of the existing service system. To learn about mental health and other service experiences of people with IDD-MH, four data collection methods were employed: (1) an online survey, (2) discussion groups, (3) phone-based family caregiver and self-advocate interviews, and (4) a review of Medicaid claims data provided by SCDDO. The identities of all participants in this evaluation are confidential.

Like any form of healthcare, resources are needed in all elements of a person's life to fully address mental health conditions. In addition to mental health treatment, IDD providers, educators, and primary health providers should also be included in service delivery. A comprehensive and integrated approach is warranted to both prevent the exacerbation of acute mental health conditions and to provide ongoing care and treatment. This evaluation focused on the effectiveness of the overall service system to both treat mental health conditions and support well-being for people with IDD, and to determine if the START model is a good fit for Sedgewick County's system of care.

There were several positive findings. There is widespread availability of the most common mental health services. Participants reported positive collaboration with police departments in many areas of the county, especially those trained as CIT responders. There is also a comprehensive behavioral health system to provide de-escalation and crisis stabilization. Evaluation participants emphasized (and demonstrated) high commitment to improving outcomes for this population, and a talented group of partners across the service system. Respondents also cited the commitment and willingness of SCDDO to acknowledge issues, invite feedback, and develop needed services and supports.

While many services were reported to be widely available in Sedgwick County, they were also reported as inadequate to meet the needs of the IDD-MH population. Overall, participants identified the need to improve services across the spectrum for people with IDD-MH, with the most frequent discussions centered on mental health (non-psychopharmacological) and crisis services. Of interest was the emphasis on the need for improvements in expertise and training

to expand the capacity of mental health and crisis providers to better treat people with IDD as well as the need for improved collaboration between the IDD and mental health service systems. There is also a need for out-of-home services in times of crisis when inpatient hospitalization is not necessary. Home-based services and institutionalization/hospitalization are available with no options in between as alternatives or step-down from more restrictive settings. Also lacking is the support needed to transition people back home after hospitalization to ensure success.

A concern identified by participants is that people with IDD over-rely on police and emergency departments to assist in times of mental health crisis. Further, participants identified a pervasive need to proactively address mental health needs as they occur (crisis prevention) rather than relying on reactive (crisis intervention) services.

IDD services do not treat mental health conditions and cannot be the primary provider of mental health care for people with IDD-MH. However, IDD services that promote mental well-being and work in partnership with mental health providers are of equal importance. Findings indicate that mental health providers do not have the expertise and capacity to treat people with IDD-MH. People with IDD-MH also report that they are socially isolated from community life and have limited access to education, vocational, and recreational services, often due to lack of transportation.

All providers should expect that people with IDD are part of their service recipient population and should be included in the planning, training, and implementation of services. A formal countywide interagency agreement that outlines the infrastructure to allow for cross-systems collaboration is needed. Further recommendations include:

1. Improve access and appropriateness of the full array of services, including mental health, crisis prevention, and crisis intervention for people with IDD-MH. This includes building the capacity of providers through training, coaching, and partnerships.

2. Expand opportunities for community engagement, work, and healthy activity by improving access to transportation and specialized support for this population.

3. Develop alternatives to emergency department visits/hospitalization/incarceration.

4. Enhance existing crisis response system to develop expertise in serving people with IDD-MH and provide follow-up and prevention planning.

5. Develop cross-systems collaboration linkage agreements to ensure that all service systems work in cohesion and with efficiency to support stabilization.

6. Ongoing data collection, reporting, evaluation, and review to ensure that services are evidence informed and to monitor their impact and cost effectiveness.

7. The START model is a good fit for the extensive and impressive service systems that exist in Sedgwick County. A START program can assist with linkages, cross training, coaching, and crisis prevention and intervention services as part of the plan going forward.

START is targeted to address many of the concerns about services reported and may have both a service outcome and financial impact in Sedgwick County. For example, according to FY 2023 claims data reviewed, the average per person cost for psychiatric hospital admissions was $53,011. By comparison, Iowa START statewide services replace the use of emergency departments and inpatient admissions while providing training, outreach, linkages, crisis prevention and response services across the state for an annual per person cost of about $11,500.

Finally, it is important to include ongoing community input and engagement to ensure that citizens have knowledge and opportunity to participate in planning and provide feedback as needed. The National Center for START Services ® at the University of New Hampshire/Institute on Disability appreciates the opportunity to assist in this effort.

Introduction

This report represents the findings from a countywide evaluation of mental health services and supports for people with intellectual/developmental disabilities (IDD) and mental health (MH) service needs (IDD-MH) in Sedgwick County, Kansas. The evaluation was conducted by members of the UNH Institute on Disability National Center for START Services® (NCSS) and funded by the Sedgwick County Developmental Disability Organization (SCDDO) as part of their ongoing effort to improve services for people with IDD-MH. It was conducted with active support and input from SCDDO and citizen volunteers. The evaluation process highlights the self-reported experiences of service users, system partners, and providers regarding the effectiveness of the existing service system. Four data collection methods were employed: (1) an online survey, (2) discussion groups, (3) phone-based family caregiver and service user interviews, and (4) a review of cost data provided by SCDDO. The identities of all participants in this evaluation are confidential. Findings, along with recommendations for follow-up, are included in this report. The National Center for START Services ® at the University of New Hampshire/Institute on Disability appreciates the opportunity to assist in this effort.

Background

Across the United States, approximately 1% to 2% of the population has an intellectual/developmental disorder (IDD).[1] Between 2009-2017, one in six children were diagnosed with a developmental disability.[2] As identified in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5-TR), Intellectual Developmental Disorder is a disorder of both "intellectual and adaptive functioning deficits with a failure to meet developmental and socio-cultural standards for personal independence and social responsibility".[3] However, the term most used in the field remains Intellectual/Developmental Disability which is what we will refer to in this evaluation.

Epidemiological studies have established that the incidence and prevalence of mental health conditions for people with IDD is typically 2 to 3 times that of the general population[1], and these mental health conditions, including those associated with a high degree of trauma, often contribute to challenging behavior and, for people with IDD, aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services.[4] Studies have found that emergency service utilization such as psychiatric hospital admissions and emergency department visits are more frequently utilized for people with IDD than in the overall population.[5] When crisis support is available, responders often do not have the training and expertise to respond effectively to people with IDD in mental health crisis.[6]

The 2023 census data estimated the population of Sedgwick County to be about 528,469 people.[7] According to information provided by SCDDO, there are 2,692 people identified as eligible for developmental disability services, and of those, nearly 39% (1,049) had an identified mental health diagnosis.[8] This rate of mental health conditions is lower than national averages, which could be accounted for by several things including people with IDD not known to SCDDO or underreporting of mental illness.

Methods of Analysis

Aims

The aims of this analysis were to address the following questions:

1. How effective is the current community system of care in Sedgwick County in addressing the needs of people with IDD-MH?
2. How can the existing service delivery system be enhanced to improve services and supports to people with IDD-MH and their families?

Data Collection Methods

Four methods were employed to learn directly from the community about their experiences with the existing service system and create opportunities for constituents to provide feedback about how to address needs. Information from all four data collection methods is integrated into each service area.

Method 1: Online survey of stakeholders
Method 2: Discussion groups
Method 3: Structured Interviews
Method 4: Cost Review

Methods were reviewed and implemented in collaboration with SCDDO, and the online survey was modified based on their feedback. SCDDO played a key role in distributing the survey across the county, and they also identified potential volunteers to participate in discussion groups and family interviews.

Online Survey of Stakeholders

The online survey link was distributed to constituents across the county including, but not limited to, IDD service providers, self-advocates, mental health providers, family members,

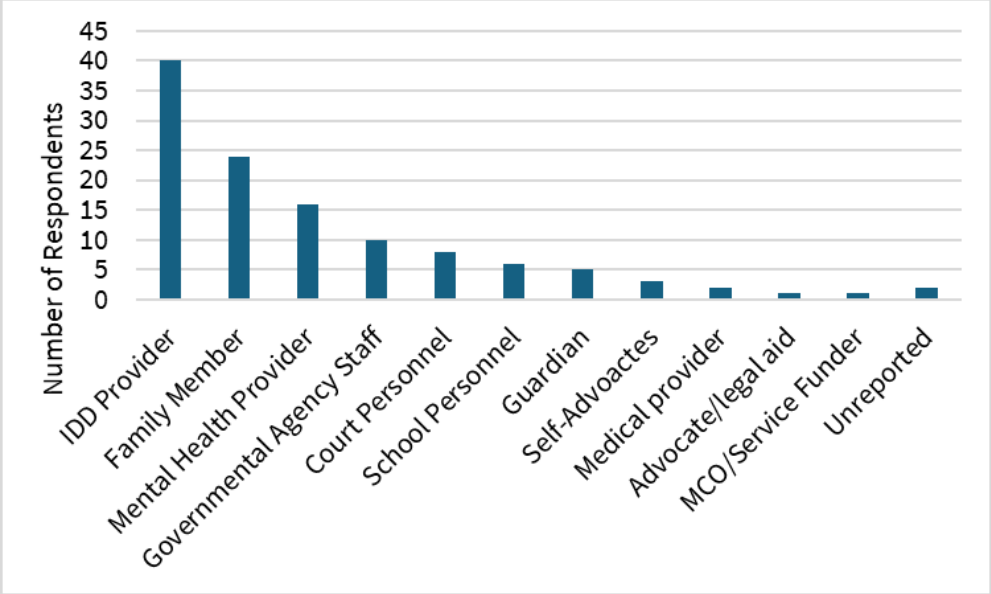
policy makers, medical personnel, juvenile justice personnel, advocates, funders, and educators. The goal was to receive feedback from as many citizens of Sedgwick County as possible.

The 3 As Framework of Effective Services[9] was employed to examine mental health and related service experiences for people with IDD-MH. The 3 As are: Access (timeliness, location, availability), Appropriateness (services match needs/wants, choice in service options, expertise of service provider), and Accountability (people are satisfied with the services, services are helpful, responsive, and flexible to meet needs).

Survey Respondents

A total of 118 volunteers completed the survey between August and November 2024. Figure 1 shows the distribution by self-reported respondent roles. Providers of MH and IDD services represented nearly half (48%) of respondents (34% [n=40] IDD providers; 14% [n=16] MH providers). Service users (mainly family members) represented 23% (n=27) of respondents, and the remaining 30% (n=35) comprised a variety of system partners including governmental agency staff, school personnel, medical personnel, court personnel, and guardians or advocates.

Figure 1: Number of Online Survey Respondents by Self-Reported Role (n=118)

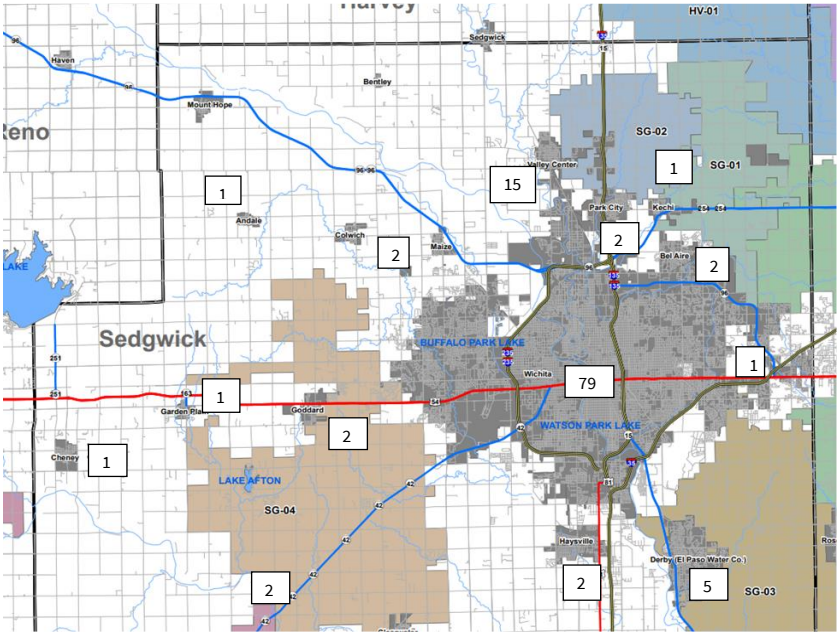


Respondents were also asked to identify the community in which they provide/receive services. While two-thirds (67%) of respondents identified Wichita as their primary location, a

total of 18 communities were represented and approximately 17% represented more rural areas of the county. The distribution is somewhat reflective of the population distribution within the county as roughly 75% of the population is in Wichita. Figure 2 shows the number of respondents by area. Some respondents specified that they provide/receive services in multiple communities, and two respondents were not located in Sedgwick County.

Every effort was made to include as many Sedgwick County citizens as possible to achieve representation in this process.

Figure 2: Number Online Survey Respondents by Location



Online Survey Design and Analysis Methods

Survey participants responded to a series of questions about mental health, IDD, and related services for people with IDD-MH. For each service, there was a five-point Likert rating scale: 1) *works well*; 2) *available, but not sufficient (service exists, but is difficult to access due to lack of providers, long wait lists, not accepting insurance, etc.)*; 3) *needs improvement (service exists but does not meet the needs of people with IDD-MH (poor service, lack of expertise, lack of training, etc.)*; 4) *do not have access*; and 5) *do not know*.

Analysis first consisted of identifying and clustering participants into four constituency groups based on self-reported role within the community system: 1) service users (family members/self-advocates), n=27; 2) IDD service providers, n=40; 3) MH service providers, n=16;

and 4) "Other," n=35. "Other" was comprised of a varied group of representatives that did not fit into the other four categories, such as medical personnel, funders, and advocates (Figure 1). A frequency distribution was done for responses to each question. To determine whether significant differences in responses between respondent groups were present, a chi-squared test was conducted for each question. The chi-squared statistical test represents a measure of the association between categorical survey responses. When differences were found to be significant, they are noted in the report. For a more detailed presentation of each question and corresponding statistical analysis tables, see Appendix A.

Second, each response category was re-coded to a numerical value so that mean (average) scores could be calculated. For this method, responses of *do not know* were eliminated to ensure that scores reflected the opinions of respondents with some exposure to the service. Scores were reported on a 0-3 scale with 0=not available, 1=needs improvement, 2=available, but not sufficient (enough), and 3=works well. An Analysis of Variance test, or ANOVA, was run to analyze overall mean differences between groups. When results were significant, they are noted in the report.

Discussion Groups

During a one-day session led by Dr. Karen Weigle and hosted by the SCDDO, a total of five breakout discussion groups were held with approximately 65 volunteer participants from across the service system. All participants were informed of the purpose of the evaluation and were provided with a brief overview of the START model and the service effectiveness framework (the 3 A's).[9]

Break out/discussion groups were asked to respond to two questions, "What is working well in the current service system for people with IDD who need mental health services?" and "What would you change or add to the system to better support the mental health service needs of people with IDD and their families?" Discussants were also asked to provide feedback based on the 3 A's, access, appropriateness and accountability of mental health and crisis services in their communities. Discussion groups provided greater depth and context to the survey results.

A qualitative analysis was conducted using a modified content analysis approach, where common ideas and viewpoints were identified and grouped by the study team.[10] This method, combined with quantitative analysis of survey results allowed for themes to emerge to help guide the findings, discussion, and recommendations identified in this report. noted in the report.

Interviews

The evaluation included a voluntary, structured telephone interview of family caregivers and self-advocates about their recent experiences with mental health services.
The Family Experiences Interview Schedule (FEIS), a survey developed by Tessler and Gamache[11], was used to conduct eleven caregiver interviews. The FEIS is a 28-question, validated, family caregiver survey that has been used in other studies.[9,12] Informants were asked to use a four-point Likert scale to rate their experiences with mental health service providers as: All that was wanted/needed; Some but not as much as I wanted/needed; Very little; or Not at all. While "did not answer/do not know" was not a choice presented, if an informant could not or did not answer a question, the interviewer marked this response. There are also two open-ended questions at the conclusion of the survey where informants were asked to: (1) assess whether their family member with IDD-MH experienced unmet service needs, and (2) give advice to service planners about the mental health needs of people with IDD.

The Person Experiences Interview Survey (PEIS)[13] was developed as part of the research study "Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities." The PEIS is based on the FEIS and was developed with direct input from people with IDD and mental health service experiences, family members of people with IDD, and mental health professionals who have experience working with people with IDD. The PEIS gathers information on similar topics as the FEIS with modifications to ensure accessibility for service recipients with IDD. It uses the same response choices as the FEIS, which makes it possible to identify similarities and differences between a person and their family member's experiences.

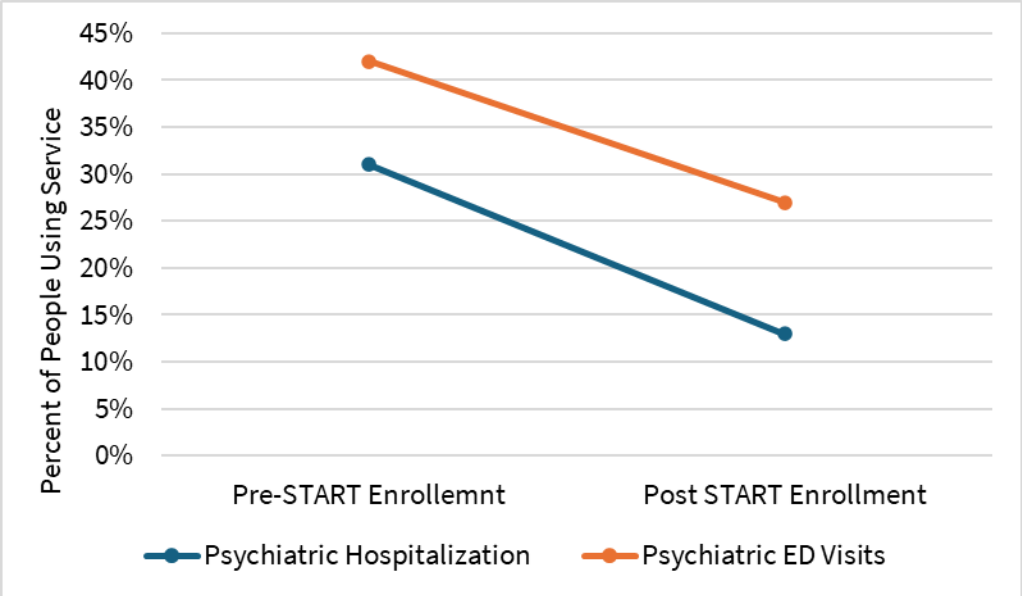
For this evaluation, fourteen family caregivers and self-advocates participated in these interviews. To protect the identities of the small number of respondents, FEIS and PEIS responses were combined. Family/self-advocate responses were consistent with survey data and feedback from discussion group participants. The interviews were designed to receive direct input from services users, and their feedback is integrated into the summary of findings that follows. noted in the report.

Cost Review

SCDDO shared service usage data for 2023 including number of psychiatric hospital admissions, emergency department use, hospital admissions, arrests/jail, mental health crisis center use (all of which involved police intervention and cost), and IDD waiver services tier usage. Rates of all these emergency service uses were compared to outcomes associated with START program crisis prevention and intervention outcomes nationally. With the expected reduction in crisis service utilization when implementing the START model (Figure

3), cost avoidance in Sedgwick County could be substantial. In applying reduction rates based on current and past START programs in other areas, projected cost reduction may range from $1.1m to $1.4 m per year, through reductions in waiver service utilization and emergency service utilization.

Figure 3: Percentage of People Using Emergency Psychiatric Services Pre and Post START Enrollment



Summary of Results

Approximately 200 volunteer citizens from across Sedgwick County participated in this process to learn about service experiences of people with IDD-MH and their families.

System Strengths

While it is important to identify areas for improvement, it is also important to recognize and build upon the strengths of the current system. Many current services within Sedgwick County already provide essential support, demonstrating effective models of care, accessibility, and advocacy. By leveraging these existing strengths, the county can create a foundation for meaningful improvements that enhance both efficiency and outcomes for people with IDD-MH and their families.

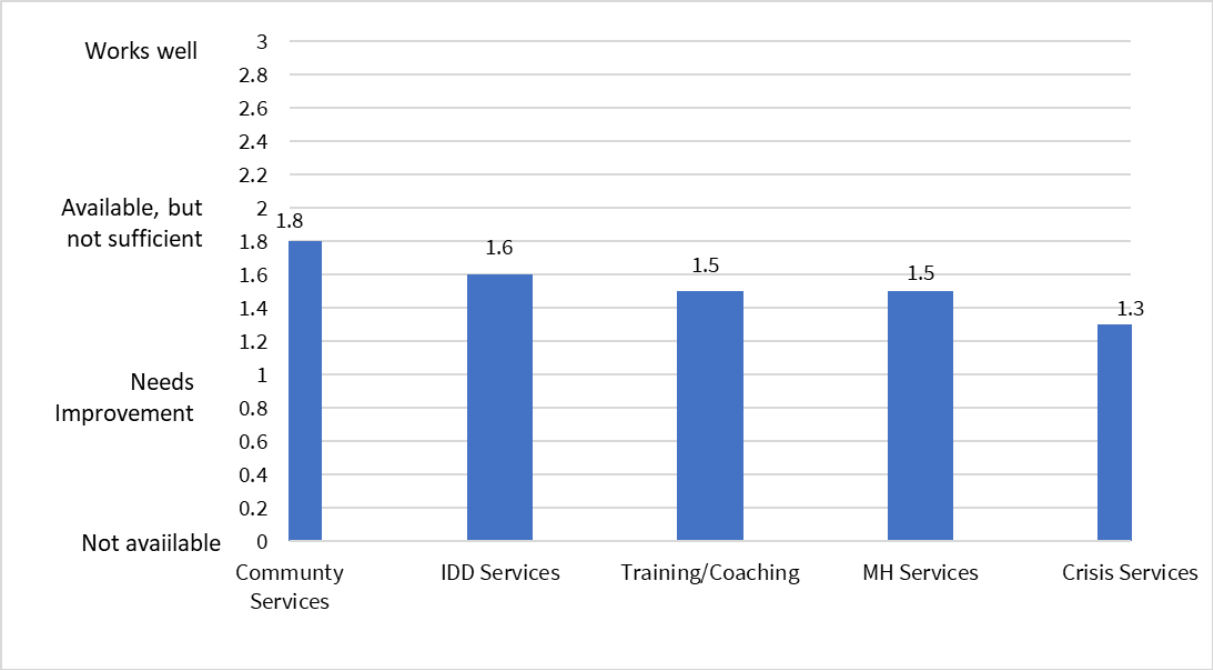
System strengths were identified during the evaluation process and grouped by the study team.[10]

The overall availability of services across the county is noteworthy. Participants reported positive collaboration with police departments, with law enforcement often cited as essential during times of mental health crisis. Evaluation participants emphasized training, such as CIT, as helpful in educating police officers in responding to mental health crises, including how to assist people with IDD. Respondents also cited the commitment and talent of partners across the county on both the IDD and mental health side who are willing to support people with complex needs as well as the willingness of SCDDO to acknowledge issues and invite feedback. Many respondents also expressed a commitment to making improvements to the system.

Findings

Analysis of 118 online surveys examined whether there were significant differences between specific service types. A comparison of mean scores for each broad service category found all services were reported to be available in Sedgwick County, but either not enough to meet the need or they required improvement in meeting the needs of people with IDD. The greatest service gaps reported pertained to crisis prevention and intervention services, followed by mental health outpatient services. Community services (medical, dental, transportation, recreation, etc.) were the most highly rated services. None of the services were rated as working well (Figure 4). **This indicates that both the capacity to provide some services and the quality of services may need to be addressed.**

Figure 4: Mean Scores for Each Service Category



Overall, participants identified the need to improve services across the spectrum for people with IDD-MH, with the most frequent discussions centered on crisis and mental health outpatient services. Of interest was the **emphasis on the need to improve cross-systems collaboration and communication across the service system to improve experiences for all service users.**

Below are a summary of results regarding these five areas of service provision:

1. Crisis Services
2. Outpatient MH
3. Training and Prevention
4. IDD and Community Services
5. System linkage and collaboration

Crisis Services

Description

An area for improvement identified by participants is response to mental health crisis. People with IDD often rely on police and emergency departments to assist during those times and would prefer responders with expertise in IDD. According to study participants, there is a

lack of proactive community crisis prevention and intervention supports in the county, resulting in an overreliance on local police departments, emergency departments, and incarcerations to respond re-actively. While the majority (79%) of those with knowledge of services reported some availability, only 7% reported that they worked well for people with IDD. Both survey and discussion group respondents expressed the need for community-based crisis services (crisis support and stabilization outside of the hospital or jail). They also emphasized that improved training and better access to outpatient mental health and other services that promote well-being, and proactively address issues as they occur, were essential to reduce the use of acute and restrictive interventions. While mobile crisis was listed as an overall mental health system asset, there was broad consensus that mobile crisis teams lacked the training and expertise to assist and evaluate people with IDD-MH in crisis, and that police response was often seen as the only option.

The online survey contained six questions regarding crisis response capacity. Table 1 provides a summary of responses. On average, overall crisis services were reported to work well (all that was needed) 7% of the time, with responses for specific services ranging from 2% (in-home crisis respite) to 18% (police response). A total of 41% of respondents reported that while services were available, they needed improvement. The services with greatest need for improvement were reported to be psychiatric inpatient units (53%) and crisis stabilization units (52%). Nearly half of respondents reported that there were either not enough services (30%) or that they were not available at all (21%). Respite services were rated as the least available (42%).

Police response was rated as the most available, and this was consistent with discussion group comments that citizens often rely on law enforcement to intervene in crisis situations. This is not surprising given that police response is part of the emergency safety net. However, it is concerning that there is such a reliance on law enforcement rather than mobile crisis and other clinicians to help de-escalate. Notably, regarding crisis services, there were no statistically significant differences between respondent groups.

Of note is that nearly a quarter of survey respondents reported that they did not know if crisis services were available to people with IDD-MH; this was nearly double for family members. As part of the survey and interviews, family caregivers were asked to rate several additional questions based on their experiences with the mental health system for their family members with IDD. **When families were asked if they knew where to get help during a crisis, 61% reported that they did not have the information they needed to access crisis assistance.**

This suggests that, even when services are available, additional outreach about available services and how to access them might be needed.

Table 1: Survey: Reported Effectiveness of Crisis Services

Services	Work well	Available, but not sufficient	Needs Improvement	Not available
Mobile Crisis	8%	38%	40%	14%
Crisis Stabilization/Hospital Diversion	3%	27%	52%	18%
Community-Based Psychiatric Inpatient Beds	5%	29%	53%	12%
In-Home Crisis Respite	2%	17%	41%	40%
Out-of-Home Crisis Respite Services	3%	14%	41%	42%
Police Response	18%	40%	38%	4%
Crisis Services (average)	**7%**	**30%**	**41%**	**21%**

When online survey respondents rated the availability of crisis service options as '*do not have access'* or *'needs improvement'*, they were asked to provide an explanation for their response (n=27). More than half (63%) reported that there was a lack of capacity both in resources and expertise, and that community crisis resources beyond the police were often not available. A quarter (25%) of those who responded reported that crisis responders lacked training or expertise to support people with IDD experiencing a mental health crisis, and 15% reported an unwillingness to admit/serve people with IDD-MH as a barrier to care. Respondents were largely positive about police response, but nearly a third (29%) reported that the reliance on police response put people with IDD-MH at greater risk for harm. The limitations of utilizing law enforcement in mental health crisis response were also emphasized, including a lack of appropriate training and consultation related to IDD-MH for law enforcement officers and the fact that jails are not appropriate holding spaces for people with IDD in times of mental health crisis. In addition, respondents expressed concern about the disruption and high cost associated with incarceration, emergency room visits, and hospitalizations.

Study participants identified a need for proactive support to prevent/de-escalate crises coinciding with increased capacity and knowledge across the service system (IDD, MH, and police) as essential elements to reduce the use of acute care. In particular, crisis respite or

similar stabilization resources, were cited by 26% as the greatest need. Participants expressed that there is no place for people to go and that people often experience multiple crisis events when no treatment is available to them.

The reported lack of crisis stabilization and response services was highlighted in connection with concerns around receiving appropriate services post-crisis. Multiple participants expressed that without outpatient treatment and crisis intervention and prevention, there were often concerns about the safety of people returning to their homes and communities. Further, this lack of capacity leads to fewer opportunities for community participation. Participants emphasized the need for crisis intervention/stabilization services as part of the continuum of care to divert from the use of law enforcement and emergency department in times of crisis.

Table 2: Discussion Group Summary of Reported Effectiveness of Crisis Services

Crisis Services	**Access (timely, nearby, enough to provide for needs)**	**Appropriateness (matches what is needed, options)**	**Accountability (acceptability change when needed, choice)**
Overall	There are not enough beds No sub-acute care services IDD often disqualifies from services		
Mobile Crisis	Unclear how to access. Do not always come	Limited training on IDD	Community is not confident that people with IDD will get what they need
Crisis stabilization beds	Often not available to people with IDD	May not match the needs of the IDD population	

		Gap in system	
Psychiatric Hospitalization (acute care)	Very limited and long waitlist	Need to develop unit that is sub-acute for longer stays People get stuck in hospital	Stays do not meet the needs of the IDD population No accommodation of the population Not clear that they are treated for their mental health needs, mostly behavior control
IDD-MH Crisis Respite	Largely not available		
Police Response	Not enough are trained Some stop responding	Some get tired of being called and do not come	Overall positive interactions with law enforcement, but frequent calls put stress on system and increase the risk of negative outcomes such as incarceration

When crises occur and other alternatives are not available, there is an increased likelihood of emergency department visits, inpatient admission, and incarcerations. Cost data provided by SCDDO indicates that, while very few people had inpatient psychiatric admissions (<3%) in 2023, the cost of those services to the system was over $1.8 million.

The cost of these psychiatric admissions alone exceeds the cost of crisis response services outside the hospital (Table 3). For example, Iowa START, operating within a similar IDD state system to Kansas, operates a START team at a cost of $11,760 per person, per year. Services include systems linkages and assessment, cross systems crisis prevention and intervention planning, coaching and outreach visits, and 24-hour mobile crisis response (this does not include Resource Center admissions). In almost all regions, the cost of one year of START clinical services is less than one typical psychiatric in-patient hospital admission.

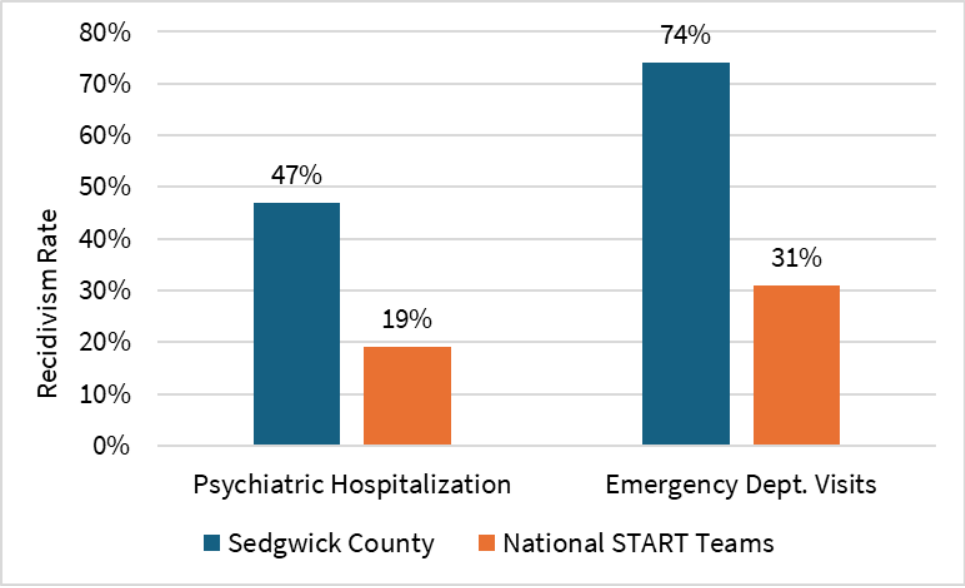
In Sedgwick County in 2023, the recidivism rate for people with psychiatric in-patient admissions was 47%. By comparison, people enrolled in START programs nationally have a hospital recidivism rate of 19% (Figure 5). Even a conservative reduction in this rate would result in some cost savings.

In addition to psychiatric admissions, SCDDO reported: 1) over 1600 incarceration days in 2023 at a cost of nearly $105,000; and 2) 805 911 calls to locations supporting people with IDD. While decreased reliance on law enforcement response has some potential for cost savings, there is a cascading benefit to the system, as more police time becomes available for other calls related to crime. Furthermore, police response to people with IDD experiencing a mental health crisis in Sedgwick County results in a higher level of care (hospital, jail, MH crisis center) in 33% of calls, compared with 19% of calls for START recipients nationally. A decrease in these highly restrictive interventions means additional hospital capacity for others in the system as well as less risk of harm and disruption for people with IDD and their families.

Table 3: Psychiatric In-Patient Claims for Mental Health 2023

Psychiatric Hospitalizations	FY 2023
# of People	34
Percentage of people who had more than one admission	47%
Total Cost	$1,802,384
Average Cost /Person	$53,011.29

Figure 5: Recidivism Rate Comparison



Implications

Findings suggest that crisis response services outside of the police are not readily available. There is a need to provide additional safety net services outside of law enforcement and to expand the expertise of existing providers to meet the needs of people with IDD. It is important to note that most crisis services were reported to be available in Sedgwick County. This is an indication that what is needed may be enhancement of capacity within the existing system of care, rather than just the addition of new services.

Outpatient Mental Health Services for People with IDD-MH

Description

Findings suggest that there is a need to increase access to community-based outpatient mental health services for people with IDD in Sedgwick County. The online survey consisted of seven questions to evaluate participant's views about outpatient mental health care. As shown in Table 4, the majority of respondents reported some access to outpatient mental health services, but few respondents overall reported that mental health services work well for with IDD. More common services such as therapy, psychiatry, and assessment were reported to be both the most available and the most effective, while expressive therapies and intensive outpatient were the least available.

There was a statistical difference between service user ratings and the provider community ratings on the effectiveness of outpatient mental health services overall. Service users were 4 times more likely to rate common mental health services (therapy, psychiatry, evaluation) as effective compared to providers ($F=5.66$), $p=0.01$(figure 6). Mental health providers were the least likely to rate mental health services as working well; the disparity was statistically significant for outpatient therapy ($p=0.01$). This suggests that while almost half of the people receiving therapy, psychiatric services, and evaluations find them effective, the mental health providers themselves are not confident in their ability to be helpful.

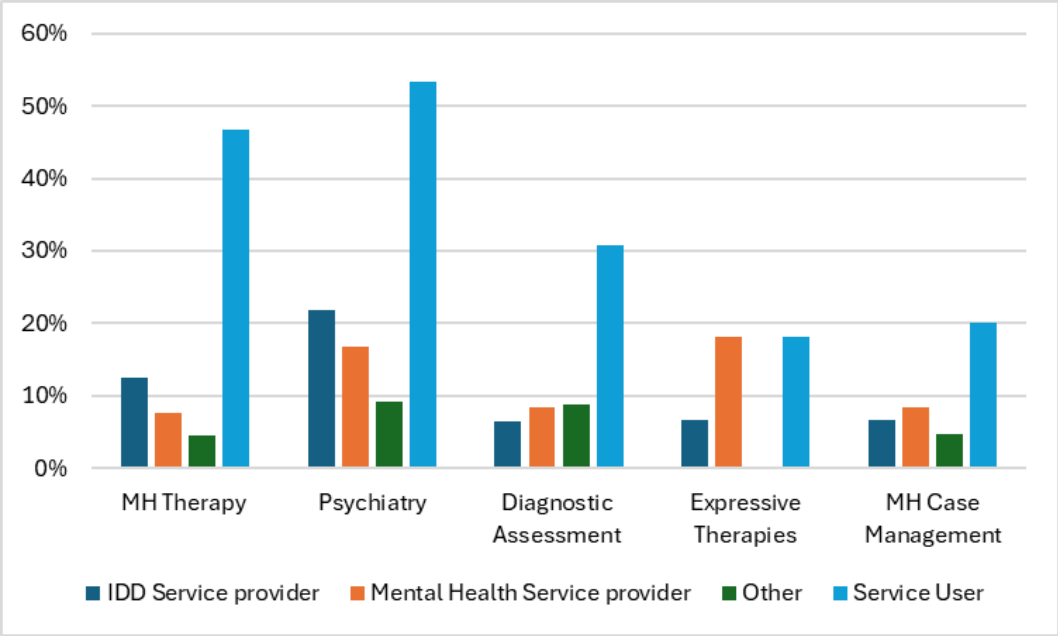
While overall, most survey respondents (87%) reported access to some mental health services, only 11% reported services worked well for people with IDD-MH. However, service users who did receive outpatient mental health services were much more likely to report them working well. This suggests that the provider community may be underestimating the positive impact of access to mental health services for people with IDD and their families. This discrepancy could also be the result of a lack of information provided to service users on mental health treatment options and expectations. It could also be the result of historical trends in under-diagnosing mental health conditions in people with IDD and attributing

dysregulation as behavioral rather than as a symptom of mental health conditions, and some providers still express concerns about the ability of people with IDD to meaningfully participate in therapy. Finally, service user participants in this evaluation were self-selected and may represent a group that is more connected to the services system and have or are advocates. **Participants noted that many mental health providers were reluctant to serve people with IDD, citing lack of training and expertise. For those who are willing and able to provide care, long waiting lists were an obstacle.**

Table 4: Survey: Reported Effectiveness of Outpatient Mental Health Services

Services	Work well	Available, but not sufficient	Needs Improvement	Not available
Outpatient MH Therapy	16%	34%	46%	4%
Psychiatry	23%	27%	44%	5%
Diagnostic Assessment	11%	34%	49%	5%
Expressive Therapies	9%	26%	41%	24%
Substance Abuse Treatment	5%	37%	42%	17%
Intensive Outpatient MH Therapy	3%	31%	42%	25%
MH Case Management	8%	27%	55%	10%
MH Services (average)	**11%**	**33%**	**44%**	**13%**

Figure 6: Survey: MH Outpatient Services* Work Well by Respondent Groups



*Most service users reported to be unfamiliar with substance abuse treatment and intensive out-patient.

Like crisis services, many other respondents emphasized the need to build the capacity of existing mental health providers, with 44% on average stating that there are available services, but they need improvement, and 33% reporting that there are not enough mental health services overall. It is noteworthy that less than 5% of survey respondents reported that common mental health services (psychiatry, therapy and assessment) were not available.

Survey respondents who rated the availability of mental health services as '*not available*' or '*needs improvement*' were asked to provide their thoughts on the perceived service gaps across Sedwick County. Of those that commented (n=22), more than a third (36%) reported an overall lack of available providers willing to treat people with IDD, and over a quarter (27%) reported that providers often lacked training and expertise in IDD. Obstacles to access such as waitlists, lack of insurance, and difficulty navigating the mental health system were also cited as barriers to treatment. One respondent reported. "too many silos, not enough understanding of how MH providers can provide treatment and support."

As part of the service user interviews (n=14), family members and self-advocates were asked several questions regarding the availability of mental health services. When asked, *"Were the available mental health services for you/your family member the ones you thought were*

needed?" only 29% responded that everything they needed was available, and 75% reported limited options for mental health services.

However, consistent with survey results, when asked to report overall satisfaction with mental health services, 76% of family members and self-advocates asked reported that they were all (47%) or somewhat (29%) satisfied, particularly with providers who understood IDD. Participants reported that limited preventative mental health services likely contribute to high rates of medication use for people with IDD-MH as well as an increased risk for law enforcement involvement, emergency department visits, and incarceration.

Table 5: Discussion Group Summary of Reported Effectiveness of Outpatient Mental Health Services

Outpatient Services	**Access** **(timely, nearby, enough to provide for needs)**	**Appropriateness** **(matches what is needed, options)**	**Accountability** **(acceptability change when needed, choice)**
Mental health outpatient Services	Very hard to get • Long waitlists • Not enough • Insurance issues	Does not have training Does not adapt to the IDD population	Long waits for services Lack of expertise Lack of providers

A number of discussion group participants stated that for many people with IDD, medication management is the only service offered to help manage mental health symptoms. SCDDO provided a summary of mental health expenditures for people receiving Home and Community-Based Services (HCBS) through SCCDO in 2023. In 2023, a total of 482 people, representing 31% of the IDD eligible samplefor that period, were prescribed psychiatric medications at a cost of more than $5 million a year.

Table 6: Prescription Drug Claims for Mental Health FY23

Psychiatric Medication Claims	Total
# of People (% of HCHS population)	482 (31%)
Billed Amount	$5,122,693
Average Cost /person	$10,628

Of note, is that SCDDO cost data reports that only 20% of those receiving services had a mental health outpatient service claim (compared to 31% for medication claims). This suggests that some people receiving psychiatric medications are likely receiving them through private providers or primary care providers or that medications may be prescribed by primary care physicians or other non-psychiatrists. This was consistent with survey data in which 32% of family respondents reported that psychiatric medications were prescribed by someone other than a psychiatrist or psychiatric prescriber; 30% of those family respondents reported that a lack of psychiatric providers was a barrier to accessing medication.

Implications

In discussion group and surveys, multiple evaluation participants indicated that Sedgwick County has a strong commitment to behavioral health services and a robust network of providers in the community. However, it was reported that for people with IDD, mental health treatment is often limited to medication and that services such as intensive outpatient mental health and substance abuse treatment often exclude people with IDD. Furthermore, expressive therapy which includes evidence-informed, effective practices which often promote mental health in people with IDD[14,15] is often missing from the service continuum. **Finally, outpatient therapy is seen as valuable by those who can access it; therefore, accessibility of these services to people with IDD is an important need.**

Access to a full array of outpatient services was identified as a necessary element in preventing the need for crisis services and restrictive placement options.

Training and Prevention

Description

Across all data collection methods was the reported need for increased training and crisis prevention and response services. Both survey responses and discussion group feedback highlighted the need for crisis prevention education, reporting that there is very little formal

training for caregivers to address a situation to prevent or avoid a crisis, and while they largely rely on personal experience to assist in responding to crisis, there is mixed success.

The online survey contained three questions designed to assess access to:

1) *Staff Training and Development*
2) *Crisis prevention and intervention planning*
3) *Family education on mental health conditions and where to go for help*

As seen in Figure 7 below, about 25% of survey respondents reported that they had no access or did not know about training, crisis prevention and intervention planning, and family education services. IDD providers were significantly less likely to rate mental health providers as adequately trained than the mental health providers themselves and service users.

Overall, survey respondents reported that improvements in mental health training and education are needed to effectively support people with IDD, and that there is a lack of capable mental health crisis prevention and intervention support with knowledge of IDD-MH. Survey respondents reported that families often lacked information about mental health conditions and where to get help. Family caregivers were asked "*How much information did you receive from your family member's mental health professional regarding his/her illness?*" and less than half (45%) felt that they got all the information they needed.

Figure 7: Training, Crisis Prevention, and Education

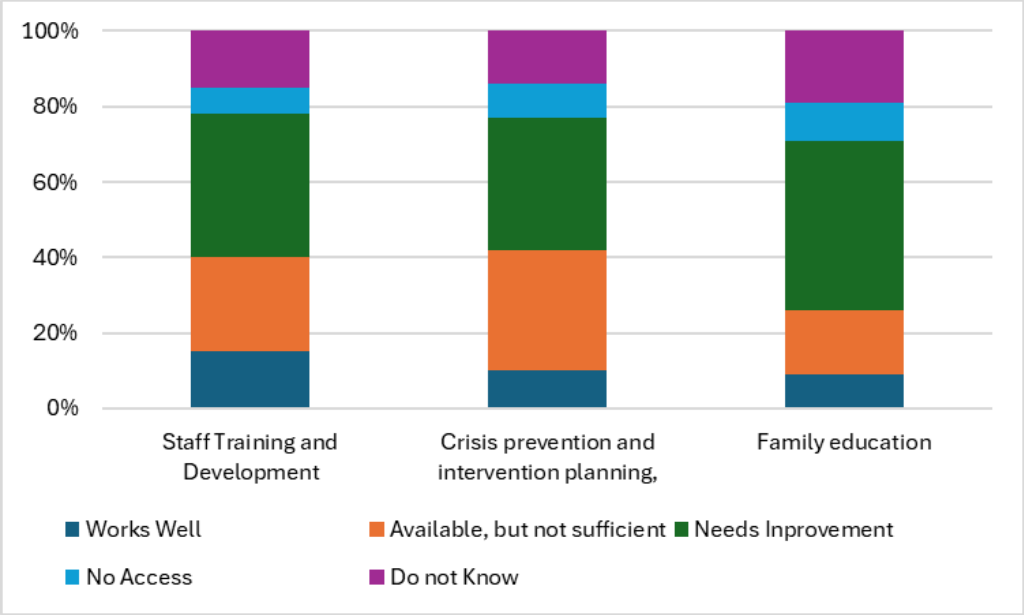


Table 7: Survey: Reported Effectiveness of Professional Training and Education by Respondent Group

Services Work Well	Service Users	IDD Providers	MH Providers	Other	p-value
Trained Mental Health Staff	38%	3%	20%	10%	0.04
Crisis Prevention and Intervention	24%	3%	13%	7%	0.08
Family Education/information	14%	6%	13%	7%	0.85

Overall, there is a reported lack of providers who are qualified to offer support in times of crisis for people with IDD-MH and overreliance on police, leading to dangerous situations for the individual, caregivers, and direct support staff. Additional training on crisis prevention and intervention was suggested to bolster community-based support for people with IDD-MH in times of difficulty and avoid the need for use of jails and involuntary commitments at hospitals. Furthermore, many reported the need for additional training to address the needs of people with IDD-MH, as current mental health treatment approaches are reported to be ineffective because they are not adapted and modified for people with IDD. This is an interesting contrast to caregiver/service user survey responses, suggesting that when they were able to access mental health services, they were acceptable. The need for trauma-informed care was also noted.

Implications

Greater capacity to understand and support people with IDD who are experiencing a mental health crisis is indicated. This includes the development of training and capacity building approaches to effectively intervene in times of difficulty, including stabilization and evaluation approaches that can be used in the person's ordinary settings as well as training to help avoid crisis events, including outpatient mental health services, support for caregivers and families, and improving the quality of life and wellbeing for those served.

IDD and Community Services

Description

The final theme to emerge was the need for greater access to all IDD and community services for people with IDD-MH. Respondents reported opportunities that focus on emotional well-being are needed such as employment and social/recreational activities to improve quality of life and decrease mental health problems and crises. However, access is reportedly difficult, particularly for people with IDD-MH who may need additional support.

The online survey asked respondents about the effectiveness of IDD services. As shown in Table 8, most IDD services were reported as widely available. The biggest access issue was for respite services (in-home, overnight, and out of home), of which 27% of respondents reported no access. For all other services, 92% of respondents reported access and 20% reported that they worked well. The biggest concerns for IDD services were cited as long waiting lists for access and staff shortages. Respite was the single most frequently mentioned service need (26%).

Table 8: Survey: Reported Effectiveness of IDD Services

Services	Work well	Available, but not sufficient	Needs Improvement	Not available
Residential Services	25%	34%	36%	5%
Home & Community-Based Supports	25%	28%	42%	5%
Adult Day Services	27%	31%	37%	5%
Pre-Vocational Services	21%	34%	37%	8%
Supported Employment	16%	33%	39%	13%
IDD Behavioral Supports	15%	23%	47%	15%
Targeted Case Management	34%	35%	30%	1%
In-Home Respite	8%	24%	46%	22%
Out-of-Home Respite	1%	17%	50%	32%
Self-Directed Supports	18%	30%	44%	8%
Agency-Directed Personal Care or Supportive Home Care	14%	26%	52%	9%
Enhanced Care Services	4%	16%	52%	28%
Specialized Medical Care	11%	28%	49%	11%
IDD Services (average)	**17%**	**29%**	**42%**	**12%**

Table 9: Survey: Reported Effectiveness of Community Services

Services	Work well	Available, but not sufficient	Needs Improvement	Not available
Medical Care	31%	51%	17%	1%
Dental Care	18%	41%	37%	4%
Transportation	15%	29%	46%	11%
Recreational Activities	26%	34%	32%	7%
Work/Volunteer Opportunities	16%	40%	39%	5%
Community Services (average)	**21%**	**39%**	**34%**	**6%**

When online survey respondents rated the availability of service options as 'not available' or 'insufficient,' they were asked to provide an explanation for their response. Respondents cited staffing shortages as the biggest barrier to access especially for people with complex needs, and over a quarter (28%) cited transportation difficulties as a barrier to employment opportunities, recreational activities, and medical care, including mental health care access. Over a quarter (26%) of respondents reported that people with IDD-MH were less likely to have access to needed IDD services, limiting their opportunities for community inclusion. Access was reportedly limited due to providers feeling a lack of appropriate training and resources to effectively include people with IDD-MH and meet their needs. In these situations, people in services often have high caregiver ratios to "manage" the person when they are experiencing mental health symptoms; this is costly and does not promote the person's or caregivers' well-being.

Implications

Overall, there was an expressed need for more meaningful community engagement, social activities, and employment. Within all discussion groups, the lack of staff was identified as a contributing factor to mental health challenges that then lead to fewer opportunities for people with IDD to thrive in their community. **The despair people feel when excluded was described as a trigger for mental health concerns for some people and an improvement in quality of life would likely decrease the need for mental health and crisis services.**

People with IDD-MH are reported to be the last and least served by the IDD service providers, especially with regard to services that promote community inclusion.

IDD-MH Cross-Systems Linkages

Description

Cross-systems collaboration and coordination emerged as a major theme within discussion groups. **Group participants cited a lack of coordination between the IDD and MH systems as a barrier to care**. Respondents reported difficulty in navigating within and between the mental health and IDD systems. Family caregivers reported that the lack of recognition that people with IDD may also have mental health conditions, and that the lack of collaboration between service systems exacerbate the need for crisis services because people do not get the preventative or ongoing mental health treatment they need when they need it.

Survey respondents also reported that the lack of collaboration across systems made discharge from hospitals more difficult. Of those survey respondents who noted difficulty with hospital discharges (68%), nearly three-quarters (71%) stated that lack of coordination and discharge planning was the primary barrier and could increase length of stay. It should be noted that feedback on the benefits of hospitalization showed that people with IDD-MH may not always benefit from inpatient treatment as well. Respondents noted that people were often discharged from the hospital without sufficient follow-up and without ensuring the health and safety of the person served and their families/caregivers. Additionally, IDD providers are often reluctant to serve people with IDD-MH at discharge due to fear and lack of support and safety planning. There is a clear need for improved cross-systems communication and planning to ensure: people get what is needed when receiving inpatient psychiatric care; hospital staff are supported and prepared to serve those being admitted; caregivers (both family and paid residential providers) are supported and educated to provide for a safe return home; and the person being discharged is aware of plans and any expected changes upon discharge and return home.

In addition, participants reported barriers in system navigation to access services. When FEIS (interview) respondents were asked about satisfaction with their role in their family member's treatment, only 36% responded that they were completely satisfied and 36% reported that they were not satisfied at all. Family members pointed to stress and exhaustion related to system navigation as an important reason for their dissatisfaction.

Implications

1. Collaboration between providers of care was a major need identified. The lack of role clarity was frequently cited as a barrier, with respondents reporting a lack of shared responsibility between IDD and MH service systems. Family caregivers reported feeling like they needed to pick one system and that there was little knowledge of how the two could work together.

Limitations

The Sedgwick County service system evaluation provides valuable feedback regarding service experiences of many community partners regarding the service experiences of people with intellectual and developmental disabilities and mental health needs and their families. The brief time of the study, number of participants, and the use of volunteer respondents limit the generalizability of the findings.

An important limitation is the participation by only a small number of people with lived experience in IDD-MH and family caregivers. Accessing those who receive services and interact with these systems of care provides valuable insight to guide growth and improvement of the current systems of care. Those who participated are likely those with the most resources (ability to access notices and requests, respond via internet, time for interviews, and ability to travel to group discussion sessions) and thus are not likely representative of most people with IDD-MH and families in the County.

Another limitation is the relatively few mental health providers who participated. In some ways, this reflects the viewpoints of those who did participate and rated themselves as less effective in working with this population.

Finally, the respondent pool was limited to those people known to SCDDO or connected with services in Sedgwick County. Given population data and typical incidence of IDD-MH, there are likely many others in the County who were not represented.

Conclusion/Recommendations

Approximately 200 people across Sedgwick County, Kansas participated in the evaluation of mental health and related service experiences of people with IDD-MH in an effort to guide the continued improvement of services in the county.

The 3 A's Framework of Effective Services[6] (Access, Appropriateness, Accountability) was employed in this examination. Group discussion and surveys were conducted to receive and evaluate direct feedback from citizens of Sedgwick County. While there were some differences between groups represented in the study, the findings indicated that, for the most part, most services require improvements in all three measures of service effectiveness.

Access to the full array of mental health services needed to support and treat mental health needs is key to reducing the use of emergency rooms, incarceration, and police as crisis response. In addition, it was reported that lack of access to community-based services toward community inclusion and meaningful life experiences (e.g., employment) undermines well-being and contributes to mental health service needs. There were mixed perceptions about access to services, often dictated by whoever was asked.

Appropriateness or goodness of fit of the services to meet the needs of the IDD-MH population was considered by all as a major obstacle to service effectiveness across the board. There was consistent concern expressed across services, systems, and constituents that capacity to serve people with IDD and mental health needs was either very limited or did not exist, namely there is an overall lack of expertise, experience, and personnel to provide services that meet the needs of the IDD-MH population. Several participants pointed to the need to improve the capacity of the existing system through more varied service options and training to support mental health and IDD services.

Accountability on the part of the service system as a whole to provide needed services was presented as limited. It was reported that mental health providers may not always provide mental health services outside of medication because they report that people with IDD could not benefit from those services or that they had no specially trained therapists or practitioners. IDD providers may be reluctant to include people with IDD-MH in vocational and recreational services because they believe this requires additional personnel that are not available, or the person has challenges that they could not address due to lack of training and capacity. Linkages and practices to ensure people who need access to care were able to navigate the system were frequent barriers reported.

Recommendations

It is important to note that there was a report of services available, but also a consistent report that existing crisis services need to improve in their capacity to support the IDD population. This is an indication of the need to enhance the capacity within the existing system of care rather than the addition of new services, except for development of: alternatives to inpatient admission, police, or jail in response to mental health crises; crisis prevention and intervention services; and cross-system collaboration.

Based on the data presented, the following elements should be considered:

Alternatives to hospitalization/Incarceration

This includes crisis prevention, immediate crisis response, evaluation, and alternatives to hospitalization for out-of-home stabilization. The county should consider the development of stepdown and mental health respite services that include consideration of best practices, inclusion, and accommodation of people with IDD. Some START teams develop what is known as a Resource Center to specifically address the need for alternatives to higher levels of care, support transitions out of higher levels of care (hospitalization), and provide respite for families.

https://centerforstartservices.org/start-model/start-therapeutic-supports-overview

Response to urgent needs and follow-up

Rapid and accessible intervention provided by trained responders is needed to address immediate crisis events, to prevent the next crisis from occurring, and to reduce restrictive interventions. If START were adopted, services could be embedded within the existing crisis response network. START staff would respond to all calls for those enrolled and could be available to consult with existing mobile crisis responders on other calls involving people with IDD.

Enhanced training and professional development opportunities across the services system

Capacity building across the service spectrum, including IDD, MH, law enforcement, and primary health providers should be a targeted goal. This is an opportunity to enhance the services provided by both mental health and IDD providers in supporting people with IDD-MH and complex needs. Training and education as well as coaching and support is also needed for families and people receiving services to use evidence-based strategies to prevent crises

and intervene effectively when prevention is not possible. Training should focus on the mental health aspects of IDD.

There are many resources available to provide training needed, including training from the Link Center, The Tennessee network, and NADD. Should START be adopted in the County, training for trainers and continuous access to evidence-based training is part of what is offered by the National Center for START Services and START programs themselves. START programs offer Clinical Education Team meetings designed to train community partners from across the service delivery system and provide technical support for follow-up. There is a prescribers' guide and training for physicians that is also widely used. Finally, NCSS offers professional development courses for direct support professionals, care managers, and crisis responders.

- https://www.nasddds.org/the-link-center/
- https://vkc.vumc.org/assets/files/resources/ucedd.pdf
- https://thenadd.org/
- Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities | Institute on Disability
- https://iod.unh.edu/national-center-start-services/training-professional-development/idd-mh-professional-development-series

Cross-systems collaboration linkage agreements

A formal countywide interagency agreement that outlines the infrastructure to allow for cross-systems collaboration is recommended. Agencies would include IDD, MH, education, first responders, and health care providers who would work collaboratively to engage in improved outcomes for the population. This could include a clarification of roles and responsibilities, including how to address emergency needs. Like any form of health care, no single entity can address the mental health care needs of all people with IDD. It requires a coordinated effort between all parties. Treatment of mental health conditions is only one part of addressing mental health needs. In response, providers should develop linkage agreements within local communities to improve access and effectiveness of their individual service systems. The emphasis should include access and dissemination of information to improve capacity and attainment of needed services and supports.

Service navigation

Caregivers and service users need additional information on available services and support in accessing them. Improve dissemination strategies so that those who may need the services

being developed are aware of them and can access them. Address the gap in knowledge that undermines timely access.

Data collection, reporting, and ongoing analysis mechanisms

To ensure that the care provided is effective (including cost effective), continual data collection, reporting, and review is recommended to evaluate the impact and cost effectiveness of efforts. Prior studies indicate that the most cost-effective care is provided using proactive strategies that build capacity, while the most costly and ineffective services are more often reactive and limited in scope.

Given the collaborative and innovative efforts already under way, we believe the START model is a good fit for Sedgwick County as START addresses the highlighted needs. START does not replace any existing service provider but instead supports others in building their knowledge and skills around supporting people with IDD-MH by working with each person and their system of care to develop cross-systems crisis prevention and intervention plans. The model provides assessment, outreach, training, and coaching to not only stabilize those we serve and their systems of care, but to help them thrive and achieve wellbeing. START services could be provided in partnership with existing service providers. We look forward to your feedback, and the potential for designing Sedgwick-County-specific START services.

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Appendix A: Pearson Chi-Squared Tables

Crisis Services

CRIS_MC

CRIS_MC	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	16.67	20.00	0.00	5.26	10.10
Needs Improvement	47.22	20.00	20.69	15.79	29.29
Available	22.22	40.00	37.93	15.79	28.28
Works well	0.00	6.67	6.90	15.79	6.06
Dont know	13.89	13.33	34.48	47.37	26.26
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 19.51 Prob = 0.0212

CRIS_CSU

CRIS_CSU	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	25.00	7.14	6.90	5.26	13.27
Needs Improvement	44.44	42.86	34.48	31.58	38.78
Available	13.89	35.71	31.03	5.26	20.41
Works well	2.78	7.14	0.00	0.00	2.04
Dont know	13.89	7.14	27.59	57.89	25.51
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 11.34 Prob = 0.2534

CRIS_PSYCHIP

CRIS_PSYCHIP	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	13.89	6.67	6.90	5.26	9.09
Needs Improvement	50.00	46.67	37.93	15.79	39.39
Available	19.44	33.33	24.14	10.53	21.21
Works well	2.78	6.67	0.00	10.53	4.04
Dont know	13.89	6.67	31.03	57.89	26.26
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.28 Prob = 0.4122

CRIS_IHR

CRIS_IHR	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	25.00	53.33	17.86	15.79	25.51
Needs Improvement	25.00	20.00	39.29	15.79	26.53
Available	13.89	6.67	14.29	5.26	11.22
Works well	0.00	6.67	0.00	0.00	1.02
Dont know	36.11	13.33	28.57	63.16	35.71
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.57 Prob = 0.3865

CRIS_OHR

CRIS_OHR	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	30.56	60.00	17.24	10.53	27.27
Needs Improvement	25.00	13.33	44.83	10.53	26.26
Available	11.11	6.67	10.34	5.26	9.09
Works well	0.00	6.67	3.45	0.00	2.02
Dont know	33.33	13.33	24.14	73.68	35.35
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 10.79 Prob = 0.2905

CRIS_POL

CRIS_POL	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	2.78	6.67	3.57	0.00	3.06
Needs Improvement	41.67	40.00	17.86	15.79	29.59
Available	41.67	26.67	32.14	15.79	31.63
Works well	8.33	20.00	14.29	21.05	14.29
Dont know	5.56	6.67	32.14	47.37	21.43
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 7.74 Prob = 0.5600

Outpatient Mental Health

OP_GROUP

OP_GROUP	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	5.56	0.00	3.45	0.00	3.00
Needs Improvement	36.11	66.67	41.38	15.00	38.00
Available	36.11	13.33	27.59	25.00	28.00
Works well	11.11	6.67	3.45	35.00	13.00
Dont know	11.11	13.33	24.14	25.00	18.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 20.37 Prob = 0.0157

OP_PSYCH

OP_PSYCH	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	5.56	6.67	3.45	0.00	4.00
Needs Improvement	36.11	53.33	41.38	15.00	36.00
Available	27.78	6.67	24.14	20.00	22.00
Works well	19.44	13.33	6.90	40.00	19.00
Dont know	11.11	20.00	24.14	25.00	19.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.95 Prob = 0.0922

OP_EVAL

OP_EVAL	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	5.56	0.00	6.90	0.00	4.00
Needs Improvement	44.44	60.00	37.93	15.00	39.00
Available	30.56	13.33	27.59	30.00	27.00
Works well	5.56	6.67	6.90	20.00	9.00
Dont know	13.89	20.00	20.69	35.00	21.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.95 Prob = 0.0922

OP_EXP

OP_EXP	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	13.89	13.33	13.79	30.00	17.00
Needs Improvement	36.11	40.00	27.59	10.00	29.00
Available	27.78	6.67	20.69	5.00	18.00
Works well	5.56	13.33	0.00	10.00	6.00
Dont know	16.67	26.67	37.93	45.00	30.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.51 Prob = 0.1053

OP_SUB

OP_SUB	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	13.89	13.33	3.45	15.00	11.00
Needs Improvement	25.00	46.67	27.59	15.00	27.00
Available	33.33	13.33	24.14	15.00	24.00
Works well	5.56	6.67	0.00	0.00	3.00
Dont know	22.22	20.00	44.83	55.00	35.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 8.09 Prob = 0.5251

OP_IOP

OP_IOP	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	16.67	13.33	13.79	20.00	16.00
Needs Improvement	25.00	40.00	37.93	5.00	27.00
Available	27.78	13.33	17.24	15.00	20.00
Works well	2.78	6.67	0.00	0.00	2.00
Dont know	27.78	26.67	31.03	60.00	35.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 9.33 Prob = 0.4077

OP_MHCM

OP_MHCM	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	8.33	0.00	10.34	5.00	7.00
Needs Improvement	47.22	53.33	34.48	25.00	40.00
Available	22.22	20.00	24.14	10.00	20.00
Works well	5.56	6.67	3.45	10.00	6.00
Dont know	16.67	20.00	27.59	50.00	27.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 4.79 Prob = 0.8521

Training and Prevention

TR_COACH

TR_COACH	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	8.33	13.33	3.33	4.76	6.86
Needs Improvement	41.67	40.00	36.67	33.33	38.24
Available	38.89	20.00	23.33	9.52	25.49
Works well	2.78	20.00	10.00	38.10	14.71
Dont know	8.33	6.67	26.67	14.29	14.71
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 17.60 Prob = 0.0400

TR_CSCP

TR_CSCP	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	13.89	20.00	0.00	4.76	8.82
Needs Improvement	38.89	40.00	40.00	19.05	35.29
Available	36.11	20.00	30.00	38.10	32.35
Works well	2.78	13.33	6.67	23.81	9.80
Dont know	8.33	6.67	23.33	14.29	13.73
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 15.29 Prob = 0.0831

TR_FE

TR_FE	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	8.33	13.33	6.67	14.29	9.80
Needs Improvement	50.00	46.67	40.00	42.86	45.10
Available	22.22	20.00	16.67	4.76	16.67
Works well	5.56	13.33	6.67	14.29	8.82
Dont know	13.89	6.67	30.00	23.81	19.61
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 4.76 Prob = 0.8548

IDD Services

IDD_RES

IDD_RES	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	6.25	5.71	7.41	4.31
Needs Improvement	28.95	50.00	45.71	14.81	33.62
Available	44.74	25.00	20.00	29.63	31.03
Works well	23.68	6.25	14.29	44.44	23.28
Dont know	2.63	12.50	14.29	3.70	7.76
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 20.28 Prob = 0.0162

IDDHCBS

IDD-HCBS	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	6.25	3.03	11.11	4.31
Needs Improvement	37.50	56.25	48.48	18.52	38.79
Available	42.50	18.75	18.18	14.81	25.86
Works well	17.50	12.50	21.21	40.74	23.28
Dont know	2.50	6.25	9.09	14.81	7.76
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 21.64 Prob = 0.0101

IDD_DAY

IDD_DAY	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	0.00	5.88	11.11	4.27
Needs Improvement	20.00	50.00	50.00	25.93	34.19
Available	42.50	25.00	20.59	22.22	29.06
Works well	35.00	12.50	11.76	33.33	24.79
Dont know	2.50	12.50	11.76	7.41	7.69
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 21.50 Prob = 0.0106

IDD_PREVOC

IDD_PREVOC	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	6.25	5.88	16.00	6.09
Needs Improvement	27.50	37.50	32.35	16.00	27.83
Available	30.00	25.00	29.41	12.00	25.22
Works well	20.00	12.50	8.82	20.00	15.65
Dont know	22.50	18.75	23.53	36.00	25.22
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 13.20 Prob = 0.1538

IDD_SE

IDD_SE	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	2.50	18.75	9.09	20.83	10.62
Needs Improvement	32.50	43.75	33.33	25.00	32.74
Available	42.50	12.50	27.27	16.67	28.32
Works well	15.00	12.50	9.09	16.67	13.27
Dont know	7.50	12.50	21.21	20.83	15.04
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 12.40 Prob = 0.1917

IDD_ABA

IDD_ABA	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	15.00	6.25	15.15	8.33	12.39
Needs Improvement	45.00	68.75	30.30	20.83	38.94
Available	17.50	12.50	21.21	20.83	18.58
Works well	10.00	12.50	18.18	8.33	12.39
Dont know	12.50	0.00	15.15	41.67	17.70
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 7.05 Prob = 0.6317

IDD_SUPCOOR

IDD_SUPCOOR	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	0.00	0.00	3.70	0.85
Needs Improvement	27.50	43.75	38.24	11.11	29.06
Available	40.00	25.00	32.35	29.63	33.33
Works well	30.00	31.25	20.59	51.85	32.48
Dont know	2.50	0.00	8.82	3.70	4.27
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.08 Prob = 0.1195

IDD_IHR

IDD_IHR	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	15.38	18.75	11.76	25.00	16.81
Needs Improvement	28.21	56.25	47.06	12.50	34.51
Available	25.64	0.00	20.59	12.50	17.70
Works well	5.13	12.50	2.94	8.33	6.19
Dont know	25.64	12.50	17.65	41.67	24.78
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 14.39 Prob = 0.1090

IDD_OHR

IDD_OHR	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	20.51	25.00	12.50	29.17	20.72
Needs Improvement	23.08	56.25	46.88	12.50	32.43
Available	12.82	0.00	15.62	8.33	10.81
Works well	2.56	0.00	0.00	0.00	0.90
Dont know	41.03	18.75	25.00	50.00	35.14
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 13.09 Prob = 0.1586

IDD_SDS

IDD_SDS	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	0.00	6.25	0.00	20.83	5.45
Needs Improvement	23.68	37.50	46.88	16.67	30.91
Available	23.68	25.00	25.00	8.33	20.91
Works well	15.79	0.00	9.38	20.83	12.73
Dont know	36.84	31.25	18.75	33.33	30.00
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 25.13 Prob = 0.0028

IDD_PCA

IDD_PCA	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	2.50	6.25	0.00	26.09	7.14
Needs Improvement	42.50	50.00	54.55	13.04	41.07
Available	25.00	18.75	24.24	8.70	20.54
Works well	7.50	6.25	3.03	30.43	10.71
Dont know	22.50	18.75	18.18	21.74	20.54
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 34.59 Prob = 0.0001

IDD_ECS

IDD_ECS	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	10.00	37.50	14.71	29.17	19.30
Needs Improvement	37.50	37.50	50.00	12.50	35.96
Available	17.50	6.25	11.76	4.17	11.40
Works well	2.50	6.25	0.00	4.17	2.63
Dont know	32.50	12.50	23.53	50.00	30.70
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 15.11 Prob = 0.0879

IDD_SMC

IDD_SMC	Group for Tables				
	IDD Service provider	Mental Health Service provider	Other	Service User	Total
No access	2.56	18.75	6.25	9.52	7.41
Needs Improvement	33.33	43.75	40.62	9.52	32.41
Available	25.64	12.50	18.75	9.52	18.52
Works well	7.69	6.25	3.12	14.29	7.41
Dont know	30.77	18.75	31.25	57.14	34.26
Total	100.00	100.00	100.00	100.00	100.00

Pearson Chi2 = 12.41 Prob = 0.1914

Appendix B: START Program Description

The National Center for START Services®

The National Center for START Services® at the University of New Hampshire Institute on Disability is a national initiative that works to strengthen efficiencies and service outcomes for people with intellectual and developmental disabilities (IDD) and behavioral health needs in the community. The National Center was established in 2009 at the IOD to provide technical support, clinical expertise, and training and consultation services that support the development of:

- Comprehensive Evaluation of Services & Systems of Care (local and state)
- A Systems Linkage Approach to Service Provision
- Expert Assessment & Clinical Support
- Outcomes-Based Research & Evaluation
- Short-Term Therapeutic Resources & Opportunities
- Cross-Systems Crisis Prevention & Intervention Planning
- Family Support, Education, & Outreach
- Interdisciplinary Collaboration

By supporting the development of the START model as outlined, START programs and their participants experience an array of benefits including:

- Reduced use of emergency services and state facility/hospital stays
- High rates of satisfaction by families and care recipients
- Cost-effective service delivery
- Increased community involvement and crisis expertise in communities
- Strengthened linkages that enrich systems, increase resources, and fill in service gaps

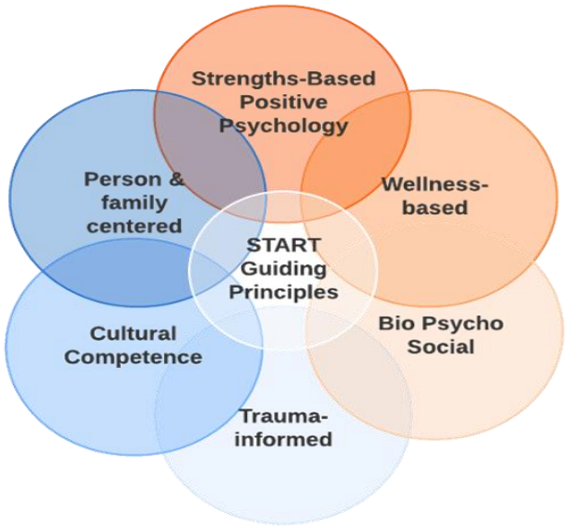
The START Model

The START program model was implemented in 1988 by Dr. Joan Beasley and her team to provide community-based crisis intervention for people with IDD and mental health needs. The model is evidence-informed and utilizes a national database. It is a person-centered, solution-focused approach that employs positive psychology and other evidence-based practices.

START is a comprehensive model of service supports that optimizes independence, treatment, and community living for people with IDD and behavioral health needs. In the 2002 U.S. Surgeon General's Report on mental health disparities for persons with intellectual/developmental disabilities, START was cited as a model program.[16] In 2016, the START model was identified as best practice by the National Academy of Sciences Institute of Medicine.[17]

Guiding Principles

The guiding principles of START are identified in literature as best practices. The following descriptions provide a brief overview of each of these principles. Each service, tool, and intervention endorsed by START is designed with these concepts in mind. Endorsed approaches should be seen as touchstones for START team members and a clear reminder of the rationale and reason behind the work of the START community.



START Clinical Team Overview

Although START program development is tailored to meet regional needs, all programs must have a START clinical team. The START clinical team operates as system-linkage supports and provides 24-hour crisis response to those enrolled in START services.

A START clinical team does not replace any one member of an existing system of support. Rather, they collaborate and facilitate change through the way they understand, interact with, and respond to the people and systems they serve. Based on the premise that there is no value in expertise if it is not shared, START Clinical Teams continually share knowledge with system partners to build capacity. The goal of START is to help the person and system achieve stability, eventually making START services unnecessary. This goal is accomplished through specialized support (e.g., outreach), assessment, and intervention that build on the principles and practices of START. Services and supports offered by START Clinical Teams include:

- Training and expertise in the mental health aspects of IDD, including Clinical Education Teams
- Systems linkage supports
- Intake and assessment activities using standardized and validated assessment tools
- Comprehensive Service Evaluations: bio-psycho-social evaluation of strengths and needs including trauma, developmental and communication-related psychological vulnerabilities, skills, natural supports, cultural considerations, etc.
- Eco-mapping, systemic analysis, and consultation
- Outreach to the person, their family, and support system to enhance team capacity
- Observation and coaching provided to teams using wellness and solution-focused approaches and the integration of positive psychology interventions in daily life
- Cross systems crisis prevention and intervention planning
- 24-hour in-person crisis response
- Medication consultation
- Facilitated team meetings and action planning
- Psychiatric hospitalization transition planning

- Access to innovative training and research initiatives led by the National Center for START Services®

START Team Design

A START Clinical Team is made up of the following positions:

Program Director (Master's Degree): Provides full-time supervision and 24/7 support to the clinical team. Serves as a liaison to community providers, coordinates all training activities, develops community linkages, and chairs the Advisory Council.

Clinical Director (Ph.D.): Provides full-time clinical oversight to the clinical team and therapeutic support services, is responsible for Clinical Education Team Meetings, and provides consultation to community providers/psychologists. coaching to Coordinators.
Medical Director (MD): A licensed psychiatrist who provides part-time consultation and training to the clinical team, physicians treating people supported by START, and the START therapeutic supports staff as needed. coaching to Coordinators.
Assistant Director (Master's Degree; dependent on program size): Oversees operations of the clinical team and therapeutic supports operations, directly supervises team leaders, and assists the Program Director as needed with the development of community linkages. coaching to Coordinators.
Clinical Team Leaders (Master's Degree; number of team leaders depends on program size) Provides day-to-day administrative support and supervision to START Coordinators, may maintain a small caseload and fills in as needed, and provides backup on-call support and coaching to Coordinators.

START Coordinators (Master's Degree): Provides direct, community-based START clinical team services to people enrolled in the program, completes required assessments, evaluations, and plans, provides 24-hour on-call crisis support for enrolled people, and regularly enters data into SIRS. coaching to Coordinators.

Therapeutic Coaching (STC) Overview
Therapeutic Coaching is designed to assess and stabilize a person in their community environment(s). START Therapeutic Coaching (STC) provides planned and emergency strengths-based, clinical coaching to primary caregivers and persons in their home setting to rethink presenting challenges. This service is part of the START crisis continuum and is only provided with the participation of the START clinical team. The START coordinator determines the need for coaching services in collaboration with the STC team leader, clinical director, the person, and their circle of support. In most cases, STC is planned in coordination

with coaches that are familiar with the person and their setting. However, in some cases, the service may be provided in a more urgent capacity. The provision of supports may occur any day of the week and will depend on the needs identified in the cross-systems crisis plan.

The goal of STC is to assist the person's caregiver by offering observational assessment of the person and their circumstances and implementing planned and/or crisis intervention strategies. Reasons therapeutic coaching supports may be accessed include:

- To provide coaching and training to family and support staff on positive, effective support strategies
- To identify biopsychosocial factors that may contribute to crisis
- To increase the likelihood that the person can maintain their preferred community living situation
- To transition successful intervention strategies to the person's home
- To provide support if a person is unable to leave their home for therapeutic intervention (e.g., symptoms of ASD keep a person from feeling comfortable in new environments), or
- For additional support prior to or following emergency Resource Center admissions (in these circumstances, Resource Center staff will participate in admissions and transition planning)

Eligibility

All persons enrolled in START are eligible for planned and emergency therapeutic coaching services if the program is set up to provide STC. Admission to STC is based on the assessment of clinical need and appropriateness. As with other therapeutic support services, supporting families is a priority.

All persons must have an established Cross-Systems Crisis Prevention and Intervention Plan (CSCPIP) prior to beginning STC services (a Provisional Crisis Plan is acceptable if within the first 45 days of intake).

The person’s primary caregiver is interested in receiving the service and coordinating supports with the STC team.

Appendix C: START Program Development Timeline

Start up (Prior to START Operations): During this process, the National Center for START Services® and identified stakeholders in the region and/or state follow research methodologies to assess the strengths and needs of the local system of support. A system analysis may occur at this point. Because START uses a systems linkage approach, it is important that the unique strengths and challenges in each region are considered when designing services.

Program Development (Year 1): Program design and action planning focus on building the START team, developing linkages and relationships with community stakeholders, developing policies and procedures, and training START staff. If a program also provides therapeutic supports (Resource Center or Therapeutic Coaching) these services are designed and built during this phase as well.

Program Implementation (Years 1 and 2): With continued guidance from NCSS, the program focuses on developing the skills of staff to meet fidelity and gain a level of confidence and expertise within the IDD and MH field. Ensuring that Coordinators are certified and focusing on preparation for program certification is ongoing and prioritized.

Program Certification Prep (Year 3): After all aspects of the START program are implemented, the team begins preparing for the National START Program Certification. At this phase, at least half of START staff have achieved coordinator certification, the program provides full on-call supports, and has internal QA procedures in place to monitor fidelity elements and mechanisms for evidence-informed decision making. The program works with their assigned NCSS project manager and the QA department to prepare for certification. This may include a "practice" certification review.

Program Certification (Year 3 and beyond): The program demonstrates mastery in established standards of START practices. More details on Program Certification can be found within the START Program Certification Manual in the Online Resource Area. An ongoing network fee for certified programs is $50,000.00 per program.

Appendix D: START Resource Center Development

Phase I (Year 1)	Meeting and Planning with START Program Advisory Council, review purpose of a START Resource Center and how Resource Center supports are accessed Identify property for Resource Center Develop building plans, permits, site development (refer to environmental considerations for Resource Center found in the START Resource Center Supports Manual) Community outreach including developing linkage agreements with community/local providers. Hire Resource Center Director, Resource Center Manager, RN Resource Center Director participates in START Coordinator Certification Training (also recommended for RC manager) and begin working toward certification
Phase II (End of Year 1 entering Year 2)	While construction and/or remodeling of Resource Center is underway: • Establish processes, practices and protocols for implementing therapeutic supports (e.g., Establishment of Therapeutic Day Schedules) • Outreach to stakeholders and updates to Advisory Council regarding Center operations, timelines, and admission process • Develop specific forms, releases, policies and protocols as mandated by licensing authority including medication administration systems • Hire START Resource Center counselors • Leadership begins using the Resource Center Training Curriculum to train new staff • Clinical and Medical Director provide training to the Resource Center and schedule for when they will be at the Center and remote contact as needed. When construction or renovations are almost complete: • Purchase of furnishings and equipment, linens, supplies, etc. in accordance with the START environmental and safety guidelines as outlined in the START Resource Center Supports Manual • Set up IT systems, computers, telemedicine equipment

	• Ensure that egress/window alerts function properly Once occupancy permit has been approved: • Schedule appointments for potential planned guests to visit Center, meet the staff, and tour the facility • Set up several "open houses" with stakeholders • Schedule planned center visits for planned guests
Phase III (Year 2)	Begin Operations First 45-60 days of operation "soft launch" of START Resource Center operations – during this period Resource Center may operate at 75% capacity, with an emphasis on planned resource center admissions. Move to "full capacity" and use of Resource Center beds in a 2 Planned/2 Emergency configuration should begin (45-60 day mark). Resource Center Therapeutic Supports leadership should be certified at this stage Therapeutic programming at Resource Center meets the requirements outlined in the START Resource Center Supports Manual
Phase IV (Year 3)	Certification Occupancy is in line with expectations of the NCSS Resource Center Therapeutic programming and guest and counselor interactions meet mission of Resource Center Therapeutic Supports guidelines and as written in the NCSS QA Programming and Environmental Checklist/Rubric

Appendix E: Acknowledgement and Supporting Literature

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the Systemic, Therapeutic, Assessment, Resources, and Treatment (START)/Sovner Center Model.

The National Center for START Services® (NCSS) was founded in 2011 at the University of New Hampshire's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services®, provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model which strives to build capacity across systems to meet the needs of individuals with IDD-MH.

Dr. Beasley is a Research Professor at the University of New Hampshire where she conducts research on the mental health aspects of intellectual and developmental disabilities. She currently leads the National Research Consortium in IDD-MH at NCSS.

The following publications provide additional information and context about the development and refinement of the START model by Joan Beasley, PhD, and colleagues.

- Beasley, J., Kroll, J., & Sovner, R. (1992). Community-based crisis mental health services for persons with developmental disabilities: The START model. The Habilitative Mental Healthcare Newsletter, 11(9), 55-58.
- Beasley, J. (1997). The three A's in policy development to promote effective mental healthcare for people with developmental disabilities. The Habilitative Mental Healthcare Newsletter, 16 (2), 31-33
- Beasley, J. B., Kroll, J. (1999). Family caregiving part II: Family caregiver professional collaboration in crisis prevention and intervention planning. Mental Health Aspects of Developmental Disabilities, 2(1), 1-5.
- Beasley, J. B. (2000). Family caregiving part III: Family assessments of mental health service experiences of individuals with mental retardation in the northeast region of Massachusetts from 1994 to 1998. Mental Health Aspects of Developmental Disabilities, 3(3), 105-113.

- Beasley, J. B. (2001). Collaborative services in Massachusetts: The START/Sovner Center Program. Impact, 14(3), 16-17.
- Beasley, J. B., & duPree, K. (2003). A systematic strategy to improve services to individuals with coexisting developmental disabilities and mental illness: National trends and the 'Connecticut blueprint'. Mental Health Aspects of Developmental Disabilities, 6(2), 50-58.
- Beasley, J. B. (2003). The START/Sovner Center Program in Massachusetts. The NADD Bulletin, 6(3), 57-59.